

Metabolism, INfection & Immunity

A clinical research study at the National Institutes of Health

"The goal of our study is to learn about how Inborn Errors of Metabolism (IEM) and their dietary complications may effect the function of the immune system".

Peter J McGuire, MS, MD Principal Investigator

Who can participate?

To join the NIH MINI Study a person must:

- Be at least 2 years of age
- Have a biochemically confirmed IEM or related disorder
- Be able to travel to and be admitted to the National Institutes of Health (NIH) Clinical Center in Bethesda, Maryland
- There are some reasons why someone may <u>not</u> be able to join the study. For details, please see our Web site: http://www.genome.gov/MINI

Other important information:

What are the benefits of participating in the study?

• There are no direct benefits to participating. However, there are a number of indirect benefits including nutritional and immunologic assessments and offering childhood vaccinations.

What is the cost of the study?

• The visits and all testing are free and there is no cost to you, your family, or your insurance company for participating in this study.

What about travel?

• If you live locally (near the NIH) we will give you some money for meals and provide lodging if necessary. If you live further away, we will pay for your transportation to NIH (plane, care mileage, train, etc), lodging, and give you some money for meals. The NIH must arrange all travel.

What the study involves:

We will review your (your child's) eligibility for the study with you on the phone. We may ask to review outside medical records.

Study participants will travel to the NIH Clinical Center. Depending on the level of participation, this may involve more than one visit.

You (your child) will meet with a geneticist to review your medical & family history and for a physical exam. We will ask you (your child) to allow us to collect urine, draw blood, and perform a detailed nutritional & immunologic assessment.

We will suggest an additional set of evaluations for some participants that we feel is appropriate based on age & level of independence. We will explain the need for those studies to you (your child).

We will offer Hepatitis A and influenza vaccines that are recommended for all IEM patients.



